

Glossary: List of Terms

504 Plan

A plan for students with special health care needs that lists accommodations related to a child's disability and required by the child so that he or she may participate in the general classroom setting and educational programs. A 504 Plan is supported by the federal law, Section 504 of the Rehabilitation Act of 1973. See Section 504. (See *Chapter 8*.)

Accessible

Easy to enter, use, or communicate with. Examples include buildings that are wheelchair accessible or programs with TTY/TDD lines for people who are Deaf or hard of hearing.

Accommodation

Service, provision, or adaptation to meet a specific need. In special education, accommodation refers to the types of services offered to a child so that he or she can fully participate in school.

Activities of Daily Living (ADLs)

Basic everyday tasks, such as bathing, dressing, toileting, eating and moving around.

Acute

In medicine, "acute" refers to a symptom or illness that appears suddenly.

Acute Care Hospital

A hospital that provides a full range of medical care, usually over the short-term, for sickness or injury.

Advocacy

Speaking up or taking action for a person, a group, or a belief. An advocate may help a family resolve problems with a school system or a health insurance plan.

Affiliation

Membership in a group or plan. Your primary care provider (PCP) may be affiliated with a hospital and a health insurance plan.

Americans with Disabilities Act (ADA)

A federal law that protects the rights of people with disabilities from discrimination in any public program, service, or building. (See *Chapter 8*.)

Apgar Score

This is a score to rate the health and strength of a baby right after birth. It measures heart rate, breathing, color, muscle tone, and reflexes on a scale from 1 to 10.

Appeal

To formally ask or request that a decision be reviewed. (See *Chapter 7*.)

Appropriate

Right, correct, or well matched to the needs of a child or family.

Assessment

The formal process used by expert professionals to learn about a person's strengths and needs. An assessment can also be called an evaluation. Assessment results are used to recommend treatments or develop care plans. Sometimes an assessment or evaluation is used to determine whether a person is eligible for a service or benefit. See *Evaluation*.

Assistive Technology (AT)

Any kind of tool or piece of equipment that helps a person live more independently. AT can be high-tech or low-tech. (See *Chapter 6*.)

Attending Physician

The main doctor who is responsible for the care of your child. Also, the experienced doctor who supervises the medical team involved in your child's care.

Baseline

A starting point used to compare observations or data. Baseline physical findings are the results from your child's first physical exam. Baseline vital signs are your child's regular heart rate (pulse), blood pressure, respiratory rate (breathing rate), and body temperature. Baseline neurological status is an assessment of your child's development, cognition, motor skills, and mental health. Baseline ancillary findings are any other important issues about your child. (See **Emergency Information Form for Children with Special Needs** in *Chapter 1*.)

Benefit

A service or type of support, usually provided through a government program or health insurance plan.

Block Nursing

See Continuous Nursing Services.

Care Coordinator

A professional who works with the family and the primary care physician and helps to coordinate care among different service providers. This work may also be called case management. A Care Coordinator also helps to arrange needed benefits and services. A Care Coordinator may also be called a Case Manager, Service Coordinator, or Care Manager. (See *Chapters 5 and 7*.)

Case Management

A service to help plan and coordinate health care. Case management is often provided by a Care Coordinator or Case Manager. (See *Chapters 5 and 7*.)

Chapter 766

The former state Special Education law in Massachusetts. The law is now called the Massachusetts Special Education Law and Regulations. (See *Chapter 8*.)

Child Life Specialist

A professional who works in a hospital and plays with children in a way to help them understand the hospital environment. A Child Life Specialist also provides fun activities and entertainment to keep children busy.

Children with Special Health Care Needs (CSHCN)

Children with special health care needs (CSHCN) are those from birth to 21 years old who have, or are at increased risk for, chronic physical, developmental, behavioral or emotional conditions. Generally these children also need more health and related services than most children.

Chronic

In medicine, the term refers to a long-term or recurring (comes back again and again) condition or illness.

Cognition

The mental process of knowing, including awareness, perception, reasoning, and judgment. The adjective is cognitive.

Community-Based Care

Services delivered locally, or as close to the child's home as possible. This type of care helps a child participate fully in all aspects of family and community life.

Congenital

Present at, or existing from, the time of birth.

Continuous Nursing Services

Skilled one-to-one nursing provided by a licensed or registered nurse for more than 2 hours per day. Sometimes called block nursing, private duty nursing, or shift nursing. (See *Chapter 6*.)

Copayment

Also called co-pay or co-insurance. A set amount of money a person pays towards a covered medical expense. A co-pay is usually paid during an office visit or for a prescription.

Conservatorship

Conservatorship is a court process and legally binding. It makes an adult (or adults) legally responsible for the financial decisions of a person who is unable to make financial decisions for himself or herself. (See *Chapter 9*.)

Coverage

The services or items provided or paid for, usually by a health insurance plan.

Developmental Delay

This term refers to when a child does not reach developmental milestones (such as walking or talking) within the same time range as most other children. Developmental delays may be generalized (all milestones), or they may show up in just one or two milestones. Developmental disability usually refers to a general delay, and to chronic conditions appearing in childhood which result from mental or physical impairment. Often this means major and life-long limitations in everyday functioning. See Impairment.

Diagnosis

The naming of a specific disease or condition according to a standard system (such as ICD-9 or DSM-4).

Dietary Supplements

Extra calories, vitamins, minerals, proteins, or other nutrients. Usually taken in the form of pills, powders, or drinks. Also called dietary additives.

Discharge Plan

A plan created by a hospital team of providers for your child before it's time to leave the hospital. The discharge plan lists the supports your child will need at the time of discharge from the hospital (such as appointments to see health care providers, plans for home health nursing, assessment for durable medical equipment). (See *Chapter 5*.)

Due Process

Due process is an important element of the state and federal legal systems. It gives you the legal right to be notified and to be heard if certain benefits or services are denied to you or your child. For example, there are regulations that make sure that parents can challenge the State's decisions about their children's eligibility for Early Intervention or special education services.

Durable Medical Equipment (DME)

Supplies or equipment that last a long time and help meet particular medical needs. (See *Chapter 6*.)

Early Intervention (EI)

A program of services for children between birth and 3 who currently have, or are at risk of having, a developmental delay. (See *Chapter 8* and **State Agencies** section of *Family TIES Resource Directory*.)

Elective Procedure

A medical test, procedure, or surgery that is not an emergency. Usually a person and doctor decide and plan the procedure together in advance.

Eligible

Meeting certain requirements for getting services or benefits.

Emergency Information Form for Children with Special Needs

The form is filled out by your child's primary care provider (PCP) and gives emergency providers the information they need to properly care for your child. (See *Chapters 1 and 4.*)

Emergency Response Plan

An emergency plan created by you and your child's primary care provider. An Emergency Response Plan includes: medical information about your child, the name(s) of your child's PCP and other important providers, where your child should be taken in an emergency, and treatment that should be provided to your child in certain situations. (See *Chapter 4.*)

Enrollment

The process of joining a health insurance plan. People enroll in health plans through their employers, through professional associations or clubs, through public benefits programs, or as individuals.

Entitlement

A service or benefit that an eligible person has a right to receive.

Evaluation

In medicine, an evaluation is a checkup, a study, or a series of tests used to determine the current status of a patient or a particular condition. An evaluation may also refer to the process used to determine whether or not a child is eligible for a service or benefit. See *Assessment.*

Family-Centered Care

Care that recognizes the family as the most central and important influence in the child's life. In family-centered care, the provider makes sure that the family participates in all health care decisions about the child. Family-centered care is one of the key elements of Medical Home. (See *Chapter 5.*)

Family Support Services

Services to meet the needs of family members. Examples include: respite care, parent networks, equipment exchanges, advocacy services, support groups, information and training, and any other assistance that enhances family life and participation in the community. See also *Family-Centered Care.*

Genetic

A trait that is hereditary, "runs in the family," passed down, or affected by genes. Genetic counseling is when a trained genetic counselor educates and counsels families about inherited genetic disorders.

Gestation

The time that a baby is carried in the uterus during pregnancy. Babies are expected to be born after 10 months or 40 weeks gestation. A premature baby is born before 37 weeks gestation. See *Premature.*

Grievance

A complaint about or dissatisfaction with a service or benefit. (See *Chapter 7.*)

Guardianship

Guardianship is a court process and legally binding. It makes an adult (or adults) legally responsible for the personal and financial decisions of a person who is unable to make these decisions alone. A guardian may or may not be a relative. Parental rights may or may not be terminated. Guardianship can be temporary or permanent, partial or complete. (See *Chapter 9.*)

Head Circumference

The measurement of length around your child's head. It helps to assess growth and development.

Health Care Proxy

Someone legally designated to make medical decisions in the event that a person cannot make them for him or herself. (See *Chapter 9.*)

Health Care Provider

Any professional who provides a health care service (such as a doctor, nurse, or therapist).

Health Insurance

A type of insurance that pays for covered health care costs. Primary health insurance is the main plan that covers most health care costs. Secondary health insurance is the additional insurance that covers costs not paid for by the primary health insurance plan. (See *Chapter 7*.)

Home Health Aide

A professional who provides home care services, including: personal care services; simple dressing changes or help with medications that do not require the skills of a nurse; help with special activities and therapies; and routine care of prosthetic and orthotic devices.

Hospice Care

The special kind of health care focused on life-limiting illness. It can be provided in the home and outside of the home in hospitals or hospice centers. Hospice care may include any of the home health services, but also usually includes both counseling services and palliative care nursing. Palliative care is focused on preserving patient comfort and dignity in the face of terminal disease. (See *Chapter 6*.)

Immunization

A substance (usually given in the form of a shot) that protects a person from viruses and bacteria. Also called a vaccine.

Impairment

An injury, deficit, or disability.

Inclusion

In the schools, inclusion or inclusive education means that all children learn together in the same schools and classrooms. Services and supports for children with special needs are built into regular school and classroom activities. See *Mainstreaming*. (See *Chapter 8*.)

Individualized Education Program (IEP)

A special education service plan for a child's school program. It is required by law for all children receiving special education services. An IEP describes an individual child's educational goals, and any services or help the child needs to meet those goals. (See *Chapter 8*.)

Individualized Family Service Plan (IFSP)

A care plan required by law for every child enrolled in Early Intervention. (See *Chapter 8*.)

Individualized Health Care Plan (IHCP)

A care plan designed to manage the medical care of a child with special health care needs in school. (See *Chapter 8*.)

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act is the federal special education law. (See *Chapter 8*.)

Least Restrictive Environment (LRE)

A term that means that your child should be educated in the same classroom and school as he or she would be in if he or she did not have disabilities. (See *Chapter 8*.)

Mainstreaming

Programs and policies to include people with disabilities in regular programs and services, such as education. See *Inclusion*. (See *Chapter 8*.)

Mandate

Something that is required by law. For example, free public education is a mandate.

Massachusetts Special Education Law and Regulations

The state special education law in Massachusetts. (See *Chapter 8*.)

Medical Emergency

A serious medical condition that results from injury, sickness or mental illness, which is sudden and severe and requires immediate treatment. (See *Chapter 4*.)

Medical Fellow

A doctor who has finished medical school and residency, and is spending 3 or more years learning to be a specialty doctor.

Medical Home

Medical Home is an idea that promotes a coordinated system of care that is accessible, continuous, comprehensive, family centered, compassionate, and culturally effective. The primary care provider shares responsibility to ensure that the child receives this kind of care. (See *Chapter 5*.)

Medical Necessity

Standards of medical practice that health plans use to make decisions about the coverage of special services or equipment. (See *Chapter 7*.)

Medical Resident

A doctor who has finished medical school and is spending 3 years learning clinical medicine. A resident is supervised by an attending doctor.

Medical Student

A student in medical school who has not yet received his or her degree. A medical student is supervised by an attending doctor.

Member Service Representative

A health insurance plan employee who can help you with questions about covered services and benefits. (See *Chapter 7*.)

Mental Health Parity Law

A special law in Massachusetts that requires most health insurance plans to provide equal coverage for mental and physical conditions. (See *Chapter 7*.)

Mental Health Counselor

A provider, usually with an advanced university degree in counseling or psychology, who can counsel you and your child on mental health – mood, behavior, and family issues.

Nurse

A nurse provides and coordinates the hands-on treatment and care of your child. A nurse also assesses symptoms and alerts the doctor to any changes in status by either writing in the medical chart or notifying the doctor immediately.

Nurse Practitioner (NP)

A nurse practitioner is a registered nurse with advanced academic and clinical training that provides primary and specialty medical care. A NP diagnoses and manages most common and many chronic illnesses, either independently or as part of a health care team.

Occupational Therapy

Treatment to help a person develop mental or physical skills for daily living, especially fine motor skills. Examples include dressing, bathing, writing, and using a fork or spoon. Occupational therapy often involves identifying and learning to use equipment that helps people with these activities.

Orthosis

A support or brace for weak joints or muscles.

Over-the-Counter (OTC) Medicine

Medication that is available without a prescription.

Palliative Care

Care that is provided not to cure, but to keep a patient comfortable. Examples include providing warmth, pain control measures, and appropriate nutrition and medications. See Hospice Care. (See *Chapter 6*.)

Parent-to-Parent Support

Parents of children with disabilities providing information and one-on-one support to each other. (See *Chapter 10*.)

Personal Care Attendant (PCA)

An independent caregiver who helps with the activities of daily living. (See *Chapter 6*.)

Physical Therapy

Treatment to relieve pain and to improve or restore movement skills and muscle function. Examples of methods of physical therapy include exercise, stretching, massage, heat, cold, water or electrical stimulation therapy.

Physician's Assistant (PA)

A health care provider specially trained to provide medical care under the supervision of a doctor. A PA can conduct physical exams, diagnose and treat illnesses, order and interpret tests, counsel on preventive health care, assist in surgery, and can often write prescriptions.

Prescription Drug

Medication that is available only with a written order from a medical provider who is licensed to prescribe medications.

Premature

Happening or arriving before the expected or usual time. A premature baby is usually defined as a baby born at least 3 weeks early, after a gestation period of less than 37 weeks. Sometimes, prematurity means a birth weight of less than 2500 grams (about 5½ pounds), regardless of gestational age. See Gestation.

Primary Care

The routine (regular) health care your child gets from a primary care provider (PCP). (See *Chapter 5*.)

Primary Care Provider (PCP)

The term for any professional who provides primary care. A primary care provider (PCP) may be a pediatrician, family physician, specialty physician, nurse practitioner, or physician's assistant. (See *Chapter 5*.)

Prior Authorization

Also called prior approval. Getting permission for special services or equipment in advance by the health plan, usually based on medical necessity. (See *Chapter 7*.)

Private Duty Nursing

See Continuous Nursing Services.

Prosthesis

An artificial device to replace a missing part of the body.

Provider Network

A group of doctors, hospitals, and other health care providers who work together with a health insurance plan to provide health care services. (See *Chapter 7*.)

Psychiatrist

A medical doctor who can counsel you and your child about mental health – mood, behavior, and family issues. If needed, a psychiatrist prescribes medications that help with mood or behavior.

Psychologist

A provider, usually with a doctorate in psychology, who can counsel you and your child about about mental health – mood, behavior, and family issues. A psychologist also does special testing to understand how your child learns, thinks, and feels.

Referral

An authorization by a health provider or health insurance plan for a person to receive care (often specialty care) from another provider. Each health plan has its own rules about referrals. Most plans have their own networks of specialists.

Rehabilitation

The process of helping a person reach the highest level of function, independence, and quality of life possible.

Respite Care

A service that provides temporary care to a child by any trained caregiver. For example, a respite care worker could be another family member, friend, or a professional caregiver. Respite care can take place in out-of-home and in-home settings for any length of time, depending on the needs of the family and available resources. (See *Chapter 6*.)

Screening

The use of basic, standardized procedures to test health, hearing, vision, developmental, behavior, and other factors to identify children with, or at risk of, disabilities or special health care needs.

Second Opinion

An evaluation by a second provider, other than your child's regular providers. You may want your child to get a second opinion if a health provider gives you a new diagnosis or tells you that your child needs a certain treatment or surgery. You may want to know if another provider agrees with the decision. Most health plans will pay for you to get a second opinion.

Section 504

A federal law that protects the rights of people with disabilities from discrimination in programs or activities that receive federal funds. See 504 Plan. (See *Chapter 8*.)

Service Date

A term used by health insurance plans for the date of an appointment, treatment, or test.

Skilled Nursing

Care and treatments by a Registered Nurse (RN) or a Licensed Practical Nurse (LPN). A nurse can provide teaching and support, perform a skilled procedure, or provide a specific therapy.

Social Worker

An individual, usually with an advanced university degree in social work, who provides counseling and aid to individuals about mental health – mood, behavior, and family issues. A social worker can also help connect you and your child with other services in your community.

Speech and Language Therapy

Treatment of conditions affecting the voice, speech, swallowing, and written communication. Speech therapy helps children who have language or speech impairments with their communication skills.

Special Education (SPED)

Special education is specially designed instruction and related services that meet the unique needs of an eligible student with a disability or a specific service need that is necessary to allow the student with a disability to access the general curriculum. The purpose of special education is to allow the student to successfully develop his or her individual educational potential. Special education is free through the public school system. (See *Chapter 8*.)

Specialist

A doctor or other health care provider with “special” training in a certain area of medical care. (See *Chapter 5*.)

Specialty Care

Care from a doctor or health other provider who has special training and experience in treating certain body systems or conditions. (See *Chapter 5*.)

Syndrome

A group of symptoms or characteristics that occur together, but have not yet been classified as a disease.

TTY (Text Telephone)

A TTY, also called TDD (Telecommunications Device for the Deaf), is a special device that lets people who are Deaf, hard of hearing, or speech-impaired use the telephone to communicate, by allowing them to type messages back and forth to one another instead of talking and listening. A TTY is required at both ends of the conversation in order to communicate.

Tertiary Care Center

A hospital that provides specialized inpatient and outpatient care.

Transition

The process of moving from one stage of life or type of service to another. For children with special health care needs, transition usually refers to process of growing older and becoming more independent in areas of health care, employment, living, and recreation. Children in Early Intervention (EI) also experience transition when they leave EI and move to school services. (See *Chapter 9*.)

Urgent Care

Care given in situations that require immediate treatment but are usually not life-threatening, such as an ear infection, sprained ankle, or flu-like symptoms.

Utilization Management

A process where health care professionals review planned hospital admissions, surgery, and other procedures to make sure they are necessary and appropriate. (See *Chapter 7*.)

Vendor

A provider, supplier, or seller. For example, a durable medical equipment (DME) vendor is the company that provides your child with equipment.

(Some definitions from Merriem-Webster Dictionary, www.merriem-webster.com.)

For more information on medical terms and medical conditions, visit:

- Children's Hospital Boston, Child Health A to Z web page, www.childrenshospital.org.
- Family Village Library web page, www.familyvillage.wisc.edu/library.htm.

Use the space below to write down additional words or terms.

Word or Term

Meaning/Definition

Abbreviations Related to Medications

Bid	Twice a day
Prn	Whenever necessary
Q	Every
Qd	Every day
Q2h	Every two hours
Q3h	Every three hours
Qid	Four times a day
Qhs	Every night
Qod	Every other day
Tid	Three times a day

Important note: If you do not understand the directions for giving a medication to your child, call your child's health care provider or pharmacist.

Commonly Used Abbreviations

ADD	Attention Deficit Disorder
ADHD	Attention Deficit with Hyperactivity Disorder
ADL	Activities of Daily Living
AIDS	Acquired Immune Deficiency Syndrome
Arc	Advocates for the Rights of Citizens with Developmental Disabilities and their Families
AT	Assistive Technology
CAT Scan	Computerized Axial Tomography Scan
CBC	Complete Blood Count
CCM	Community Case Management
CP	Cerebral Palsy
CPR	Cardiopulmonary Resuscitation
CSHCN	Children with Special Health Care Needs
DD	Developmental Disability
DME	Durable Medical Equipment
DMH	Department of Mental Health
DMR	Department of Mental Retardation
DNR	Do Not Resuscitate
DO	Doctor of Osteopathy
DOE	Department of Education
DPH	Department of Public Health
DSS	Department of Social Services
DTA	Department of Transitional Assistance (Welfare)
Dx	Diagnosis
ECG or EKG	Electrocardiogram
EEG	Electroencephalogram
EI	Early Intervention
EMS	Emergency Medical Services
EOHHS	Executive Office of Health and Human Services
EPSDT	Early and Periodic Screening, Diagnosis and Treatment
FAPE	Free and Appropriate Public Education
FTT	Failure to Thrive
GI	Gastrointestinal
HHS	Health and Human Services
HMO	Health Maintenance Organization
I&O	Intake & Output
I&R	Information & Referral
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
IFSP	Individualized Family Service Plan
IHCP	Individualized Health Care Plan
IV	Intravenous
IVH	Intraventricular Hemorrhage

LD	Learning Disability
LICSW/LCSW	Licensed (Individual) Clinical Social Worker
LRE	Least Restrictive Environment
MCB	Massachusetts Commission for the Blind
MCDHH	Massachusetts Commission for the Deaf and Hard of Hearing
MCH	Maternal and Child Health
MCO	Managed Care Organization
MD	Medical Doctor
MD	Muscular Dystrophy
MR	Mental Retardation
MRC	Massachusetts Rehabilitation Commission
MRI	Magnetic Resonance Imaging
NICU	Neonatal Intensive Care Unit
NP	Nurse Practitioner
NPO	Nothing by Mouth
OCCS	Office of Child Care Services
ORL	Otolaryngologist (ear, nose, and throat doctor)
OT	Occupational Therapy or Occupational Therapist
PA	Physician's Assistant
PA	Prior Authorization or Approval
PASS	Plan for Achieving Self Support
PCA	Personal Care Attendant or Assistant
PCC	Primary Care Clinician
PCP	Primary Care Provider or Primary Care Physician
PDD	Pervasive Developmental Disorder
PDN	Private Duty Nursing
Ph.D.	Doctor of Philosophy (a non-medical doctor)
PICU	Pediatric Intensive Care Unit
PL	Public Law
PPO	Preferred Provider Organization
PT	Physical Therapy or Physical Therapist
RN	Registered Nurse
Rx	Prescription or Treatment
SIDS	Sudden Infant Death Syndrome
SLP	Speech-Language Pathologist (Therapist)
SPED	Special Education
SSA	Social Security Administration
SSI	Supplemental Security Income
TA	Technical Assistance
TAFDC	Transitional Assistance for Families with Dependent Children
TANF	Temporary Assistance for Needy Families
TDD	Telecommunications Device for the Deaf
TPN	Total Parenteral Nutrition
TTY	Text Telephone
Tx	Treatment
URI	Upper Respiratory Infection
UTI	Urinary Tract Infection
WIC	Women, Infants, and Children Nutrition Program